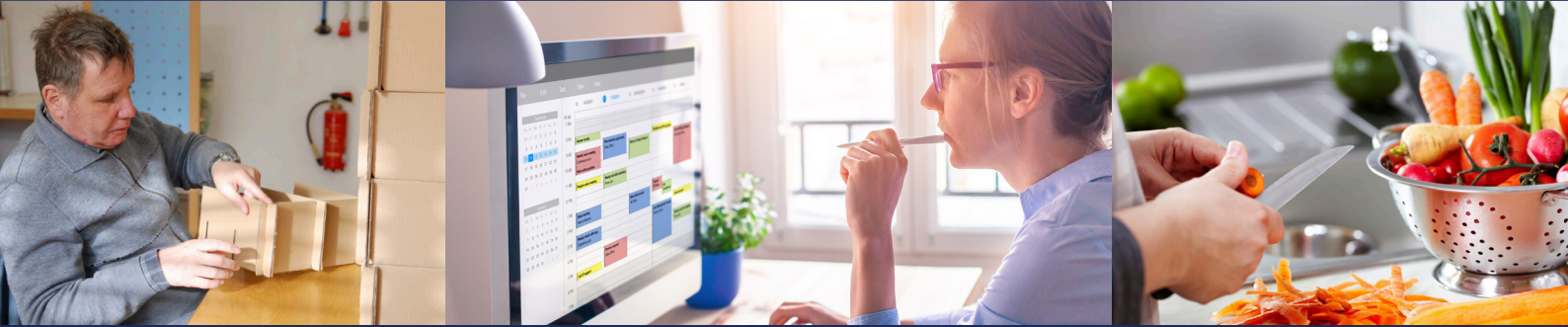




Understanding Autism

Handout 6 - Routines and managing uncertainty



An autistic person is often managing a lot of uncertainty

An autistic person may find the world and other people's behaviour confusing, inconsistent and unpredictable at times. They may need more structure, and rely on their routines and certainties for security more than most people do.

Give people time



An autistic person may need more time to get used to the idea of change, visiting unfamiliar places or doing a new activity. Uncertainties can feel very overwhelming, particularly when they are unexpected or sudden.

For example:

- Visiting a new environment like a hospital, and working out how to sign in and find the right department
- A new experience, such as having a blood test for the first time
- A road closure affecting their planned route, or an activity being cancelled
- Doing a familiar task in a different environment, such as using a different kitchen

Routines and structure

A familiar routine, such as following the usual route to work/college or a morning routine at home, can reduce the need to think, saving valuable brain power to manage any uncertainties the day may bring.

A person may find it stressful if their familiar routine is changed, or can't be completed. Unstructured times like lunch breaks and holidays can also feel uncertain and stressful.

A need for certainty

Some autistic people may need a lot of preparation in advance of a new activity or experience. Some autistic people have a strong need for things to be correct.

An autistic person will often follow the rules, as rules give certainty.

Sameness

Some autistic people may prefer the comfort and certainty of familiar choices and places. Lots of choice can be overwhelming, and some people may choose the same meal each time at a restaurant, or stick to a small range of familiar activities.

Times of stress

If a person is feeling anxious or stressed, reliance on their routines and their need for 'sameness' are likely to be heightened. A series of uncertainties through the day may lead to a person getting stressed by a seemingly minor change.

Some autistic people can find uncertainty very frightening and exhausting, and at times become withdrawn, upset or frustrated.

A strong ability to focus

Many autistic people have a strong ability to focus on tasks, but interruptions and switching between tasks can be challenging. Some people may struggle to judge when to stop, or when something is finished or 'good enough'.



No surprises !



Many autistic people find advance preparation helpful.

For example:

- Planning an alternative route in advance in case it's needed
- At the beginning of an appointment explaining the steps that will happen
- Researching parks where dogs must be kept on a lead when supporting someone nervous of dogs

Supporting autistic people to manage uncertainty

Change will sometimes happen, and visits to unfamiliar places can be necessary, or even enjoyable.

Reducing the risk of people feeling overwhelmed

- A person's initial reaction to change or something new may be to say "No". Understand that at times this response may be due to a fear of the unknown.
- A person may need a lot of time and support to think things through and make an informed choice. "It's hard to make a choice when you're terrified!"
- Some people may need detailed information about why change is happening, what the possible alternatives are and exactly what's involved in the new plan.

- Understand that a person is more likely to struggle if they've been managing other recent changes.
- Understand that a person may be better able to consider change when in a safe environment such as their home.
- Written or pictorial information can be very helpful as it's permanent and people can then process the information in their own time. We explore visual supports on page 3.
- Understand that a person may initially need extra support to get used to something new or different, such as visiting a new environment, or using an unfamiliar appliance.

Lastly, understand that a person may have less need for variety than many other people do, and that's okay !

Many autistic people prefer to focus on one task at a time

For example, when cooking a meal such as pasta and sauce, a person may prefer to cook the sauce first and then the pasta so they only have one task to focus on.

It can help to prepare in advance to avoid the potential for overwhelm, for example, choosing an outfit the day before to reduce demands in the morning.



Setting up routines and organising daily life

Tasks such as planning and cooking meals, getting to places on time and managing paperwork may seem easy for some people, but actually require quite complex 'executive functioning' skills.

Some autistic people, even very intellectual people, can have significant struggles in this area, and can mistakenly be seen as lazy, depressed, or lacking ability. Autistic people can have 'uneven abilities', and struggle with some tasks whilst excelling at others.

Some people may need help to set up their routines, to break tasks down to smaller steps and plan the order in which to do them. Lists, or other visual supports are often really helpful.



Signs of difficulties with executive functioning can include:

- Mislaying things, and forgetting things they need when going out
- Forgetting important appointments, and other things they'd like to do
- Feeling overwhelmed by tasks and not knowing where to start, even when very motivated
- Struggling to work out the order in which to do things, and keeping track of priorities
- Difficulties judging how much time a task will take, keeping track of time and getting distracted
- Difficulties with organisation, so paperwork and clutter builds up and feels out of control

Developing independence



Many autistic people do not want to rely on a supporter coming to their home to do things for them, as their home is their 'safe space'.

As well as support to break tasks down and order them, people may find it helps to establish a routine separately to doing the activity.

For example, a person may 'get into the habit' of studying by choosing a regular day and time, but do easier tasks such as reading at first, whilst they get used to the routine.

Using technology



Some autistic people use reminders on their phone or other devices to keep track of time and activities.

Some apps are designed with autistic people or executive functioning in mind. Search for 'executive functioning' online or in the app store.

Visual supports

A visual support can be as simple as a written list, a calendar on a mobile phone, a chart on the wall or even a diary.

Some autistic people like to have very detailed written schedules, which can even include activities such as 'have a bath', 'Eastenders' and 'eat lunch'. This can help people to look after their own needs. It can also help to add in less frequent tasks that are easy to overlook, such as 'change the bed sheets'.

A visual support is permanent, and takes away the need to keep track of everything mentally.

Learning skills - like cooking pizza !

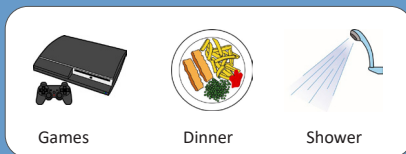
'Backward chaining' is an approach where a task is broken into small written or illustrated steps, and a person is supported to complete the last part of the task initially, e.g. 'slicing the pizza on the table'.

This gives the person the pleasure of completing the task, and previous steps can be added in over time, e.g. 'take the pizza out the oven and put onto a plate' and then 'slice it'.



Visual supports using pictures

Some autistic people, particularly people with a learning disability, may find pictorial supports are more accessible. Examples can include:



- Timetables and calendars for daily activities and events
- Guides showing the order in which to do things, like a morning routine
- Storyboards showing what to expect in new situations such as a visit to a hospital for a procedure, or going on holiday
- Rotas showing who will be coming to support them and when



Objects rather than pictures can help explain things to some people, for example, using a wooden spoon to say we're going to be cooking.

Routines and change - our experiences



Eleanor was really anxious about going into any new rooms at the college she attended. We took photos of the inside of the rooms and stuck them on the door. This helped her know what to expect, and took away that fear.



When on holiday, I find unexpected changes much harder as I'm away from my familiar home and routines. I once walked 30 minutes to a museum and found it closed. My brain shut down. I couldn't think what to do, so I just walked straight back to my hotel.



I use a very detailed schedule, and this actually helps me to be more flexible as I feel more in control of things. If something changes I can adjust my schedule rather than panic !



It really threw me when I got a new washing machine. I just couldn't work it out, and got really frustrated by getting things in the wrong order. It never occurred to me to take the dry clothes off the airer first. I've got a degree in physics, so doing rocket science would actually be easier than working out my washing machine !



I really struggle to organise myself at home. Bills go unpaid and I forget to eat sometimes. People just assume I can't be bothered, but it bothers me all the time. I've accepted I need help with this now.



I always leave early when going somewhere new, and have a back up route planned. I once arrived two hours early in a town for an appointment !



Sam's tutor at college uses a 'countdown clock' that clearly shows in red how long there is left for an activity. Sam now finds it easier to predict when activities will end and to prepare himself to move on.

I had the same packed lunch for 13 years at school. It was the one thing I could rely on every day.



I get overwhelmed with large tasks and just can't work out how to get started, even if I'm really motivated. Breaking tasks down helps, so instead of 'sorting out the kitchen' I have a list of specific tasks which I work through in order.



I use a menu planning app which has a three weekly rotating menu. This makes it easy for me to plan my shopping and cooking.



Ginny volunteers in our office one day a week. We make sure she has the same desk each time, and that her work routine for the day is explained using pictures. Shredding is her favourite job.

At college I found unstructured time in lessons very difficult. Some lessons would just be to catch up on any assignment work, and I found this very hard as there was no structure to the session.

I did not know where to start or even what piece of work to do. This caused me huge levels of anxiety. It sometimes led to me having a meltdown and going home early as I could not cope.



My university mentor, funded through Disabled Students Allowance, helped me create a detailed visual chart of what assignments I had coming up, the date they were all due in and all in date order for what was due in first. We factored in extra time for edits and proofreading. I also set reminders on my phone calendar for a few days before the assignment was due in.



I find school holidays really difficult as all my routines are thrown out. My daughter and I make a plan for each day, but I find it all exhausting and am glad when things get back to normal.



I really struggle to switch off until everything is just right. Unfinished tasks bug me constantly. Writing a to do list for the next day helps me feel like I can let go for today.

I wish I could be more flexible with my routines. I really wish I could, but I find this so hard to do. It takes me a long time to get my head around the idea of change. It helps when people show patience.

